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# On Aging, Dying, and Denying

*Delivering care to older dying patients*

DYING IN OLD AGE is a subject of distant postponable concern to most health professionals since they are interested primarily in the prevention and adequate treatment of disease. Even those who are close to the care of dying older patients are uncomfortable in confronting the specter of death in their clients. In the health professions, the overwhelming commitment of training, talent, and funds to curing and healing, although important, may weaken the thrust for better care of

the dying and render it unlikely that an older person's last days will be spent in a supportive social environment in which his death is regarded as an individual and unique event. A patient with no future at all attracts both hostility and denial. When death becomes inevitable, many health professionals withdraw from its bruising assault and redirect their efforts elsewhere.

Yet, many readers of this journal are deeply interested and involved in comprehensive health

care, which—if it is truly comprehensive—should help dying older patients as well as younger curable patients. There is a rising concern about the delivery of humane care, a push for open discussion of complex moral issues, and a growing recognition that we must openly communicate with both the terminally ill patient and his family. As a first step in overcoming our aversion to dealing with death at an advanced age, we need to examine the complex issues associated with the management of the older dying patient. That is the purpose of our paper.

### **Sociological Perspectives**

Technological and other advancements have rendered obsolete many attributes of the older person, such as his wisdom, that were highly valued in the more rural society of 19th century America. The power that the older person enjoyed in the extended family of the past has also been reduced in the emergent nuclear family of industrialized society. In modern society older parents may continue to help their children, and in turn, the children may assist their elders. The power of the older family member over family decisions, however, has faded in comparison with that of earlier decades.

Today some 25 percent of the persons aged 65 and over live alone or with nonrelatives (1). About three times as many older women as men live alone or with nonrelatives, a circumstance reflecting, among other things, the greater life expectancy among women. Older women also appear to be at greater risk of institutionalization. In the segment of the older population residing alone or with unrelated persons, social disengagement and isolation may occur. These observations suggest the need for health and social support services to compensate for the possible absence of family members of older patients facing death.

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To understand the possibilities for improving the care given the older dying person, we must consider the social climate in which the older population lives. Many older people subsist on small, fixed incomes in an inflationary economy; in 1970 half of those who were not living with their families had incomes below the poverty level. Some older citizens have been forced to retire, while others have done so voluntarily. For both groups, retirement may have entailed a reduction of activities, loss of contact with their working colleagues, and a reduced income.

A century ago about two-thirds of U.S. men aged 65 and older were still in the labor force, compared with only 25 percent today (1). The shift from having one's hours dictated by the work organization to having free time and a reduced income has implications for the quality of life of the older person. Because an older person not in the work force is no longer seen by society as being "productive," he may find himself regarded as having a lower social status. Many older people cope successfully with this transition. Socially isolated retirees seem to have the most difficulty in adjusting to their new status. Indeed, one investigation disclosed a "low will to live" in 48 percent of socially isolated retired steelworkers in contrast with only 7 percent of the retirees who were socially integrated (2). As one retired worker pointed out, "I don't worry about the next life. I've got enough hell right here." Not surprisingly, those older persons who find themselves socially devalued and isolated may experience depression and hold negative views of themselves and of life in general.

Presumably the younger person looks to the future, whereas the older person is seen as engaging in a review of his past life. Although such a review may be helpful to many older persons, for the socially isolated who have experienced social estrangement, this period of life review may parallel a process of social disengagement, of dying socially. And social death, the extreme stage of social isolation, may contribute in complex ways to biological death.

To a considerable extent modern society defies age and denies death. Our health care providers come from such a society, and therefore few can conceive realistically of their own senescence and death, even though they recognize that death is a universal phenomenon. Their training in this area has been inadequate so that they are often

only able to react as laymen to dying patients, rather than on the basis of sound academic knowledge. Thus, both at the beginning and in the midst of the professional's career, education must increasingly focus on the dynamics of senescence and dying and on management of the dying patient. When, through such education, we as health providers come to realize that our own deaths are likely to take place in a health care setting, a large step will have been taken toward improving the environment of the older dying patient.

### **Stresses of Bereavement and Relocation**

The great impact of bereavement on the health of older survivors is now well documented. In a study of 4,486 widowers aged 55 years and older, Parkes and associates found that 213 had died within 6 months after the loss of their wives (3). This figure was 40 percent higher than the expected mortality for married men of the same age. After the 6-month period the death rate of the widowers dropped to that of married men. The authors point out that "if as seems most likely, the painful effects of bereavement on physical health are a response to psychological stress, then anything that mitigates this stress can be expected to reduce the risk of its physical effects." Other research, suggesting that grief is a syndrome leading to greater use of physicians for both psychiatric and nonpsychiatric symptoms, clearly shows the need for preparing physicians, nurses, and others to deal with the physical and psychological needs of the bereaved.

Unfortunately, few health agencies use death notifications or other approaches to single out older persons who may need supportive care. Yet, health professionals and community volunteers might help blunt some of the sharp and traumatic edges of grief in the bereaved elderly. In one pilot treatment program designed to assist the bereaved, a psychiatric social worker was accepted by 90 percent of the persons who were contacted (4). More communities might organize widow to widow programs in which widowed volunteers give support to newly bereaved women, with some mutual benefit accruing to both groups.

Through what practical steps can we help the bereaved? Gerber has suggested the following approach: (a) help the person express, verbally and emotionally, the pain, sorrow, and common feelings of guilt; (b) facilitate his gradual return to

social activities with friends or relatives; (c) help him deal with such practicalities as legal problems; (d) mediate referral for health care if indicated; and (e) offer assistance in making future plans (4). Few health care providers may now be ready to give such help and many may doubt that it should be part of a comprehensive health and social support system, but such steps seem essential if we are to reduce the unnecessarily high incidence of disease and distress during bereavement.

Faced with increasing illness and reduced social support, some older persons head inescapably toward a new life within institutional walls. Thus, the issues of death and dying are for the older person often intertwined with those of living in an institution. Gustafson provocatively conceives of the "career" of many nursing home patients as that of a dying trajectory (5). Markson is among those who suggest that hospitals and comparable institutions have used other facilities, such as psychiatric hospitals, as dumping grounds for dying older persons (6). As Glaser points out, hospital beds, in which care that is technically good is given, are thus "freed up" by referring older persons to marginal institutions (7). Such institutions, in turn, have few resources to meet the complex medical, emotional, and social needs of the dying elderly.

Studies of enforced relocation suggest that moving the older patient against his or her will to another location may speed the downhill course to death. Even awaiting such a move has been shown to have negative effects. For example, Prock found that people awaiting relocation to an old age home had a worse psychological status than those who were already institutionalized (8). Among their characteristics were "general anxiety and tension, high emotional reactivity, a sense of helplessness and powerlessness, a tone of depression accompanied by low self-esteem, interpersonal patterns suggesting an active withdrawal from those around them, and some signs of ego disorganization. A quality of 'my life is over' permeated the waiting list group."

Older people waiting to move to a new location can best be described as dying socially. The anticipatory grief associated with the expected loss of familiar surroundings and of close friends, relatives, and even of staff members of an institution where they have been living may precipitate adverse biological changes. One resident of a

medical care facility, when informed that she had to be moved because the facility was closing down, said that she would rather die than move to the new nursing home. Two days later she was dead; whether by coincidence or cause and effect is not known. Clearly, the increased morbidity and mortality that may occur in older people confronted with involuntary relocation should be prevented whenever possible. Since the older patients who are to be relocated are the persons most concerned in such moves, it helps to give them an active role in the advance planning and decision making about the move and to have them visit the new facility before they actually move (9). The resulting lessening of uncertainty and fear reduces the patients' anticipatory grief and its adverse effects.

### Site of Death

Advances in technology, the concentration of modern, complex medical equipment in major hospitals, and the wide variety of specialists engaged in delivering care are among the factors that have increased the proportion of deaths occurring within institutional walls. The encouragement that insurance gives to hospitalization, the paucity of home health care services, the loss with the advance in age of many friends and relatives, and the limited financial resources of many of the elderly may further contribute to this pattern for the older population. Lerner reports that for the nation as a whole, 50 percent of all deaths in 1949 and 61 percent of all deaths in 1958 occurred within institutions (10). Today the figure is probably 70 percent.

The way the environment of the older dying person is organized within an institution (including the beliefs, values, and behavior of the institution's staff), its organizational goals, and the available resources considerably affect the care and support he is given. In the general hospital, for example, the dying patient and family members undergo an experience that to them is unique and moving, but that is more common and less personal to the staff. Routine patient care and routine administrative activities continue, accompanied perhaps by impersonality or even a withdrawal of interest from the dying patient. In long-term institutions, the older person may be assigned to the "vegetable garden"—an area where the soil is rarely tilled sufficiently to nurture dignity and social support in the face of death.

Kastenbaum calls for professionals to recognize that many of the dying are conscious of their surroundings and miss those interpersonal relationships which have steadily been withdrawn (11). On some wards older dying patients may be treated as if they were already dead, or at least as if they were deeply unconscious, childlike, and unaware of what people were saying around their beds.

Hinton and others have noted the covert reluctance of some staff members to care for the dying person (12). Markson described hospitals in which a combination of great age and terminal illness apparently would cause a patient to be despised by medical and lay personnel alike. Unless death came on schedule, the hospitals would suggest transfer of the patient to a State mental hospital (6). Even in an intensive care unit of a hospital where younger patients predominate, the staff may use detachment, constant activity, and other measures to cope with the frequent deaths that occur. Coombs and Goldman describe how laughter helped the staff of one such hospital unit relieve some stresses, while other staff members were helped by intentionally losing themselves in their work (13). They found that the delicate balance between detachment and concern was most often tipped by the patient's age; the weight of many years appeared to tip the scales decisively in the direction of detachment.

In a study of possible "dead on arrivals" in a hospital emergency room, Sudnow found that "the older the patient, the more likely is his tentative death taken to constitute pronounceable death. . . . Very old patients who are initially considered to be dead solely on the basis of the ambulance driver's assessment of that possibility were seen to be put in an empty room to wait several moments before a physician arrived. . . . The older the person, the less thorough is the examination he is given. . . ." (14). Routinized practices like these emerge as an organization seeks to meet curative, youth-oriented goals, goals that, in turn, may reflect the views of the broader "gerontophobic" society.

No institution is immune to the social stereotypes of its surrounding culture. Comfort is of the opinion that a fear of aging and confrontation with one's own mortality are often reflected in a "gerontophobia" that adversely affects the care of the older patient (15). Death in an old patient may sometimes be treated as a social gain

for all concerned since resources will no longer seem to be drained away by a person considered to be of low social value. Yet an emphasis upon cure, however essential it may be for all health institutions, should not prevent them from giving the humane care needed by the older dying patient and his family.

### A Chance to Live

The elderly patient dying in a humane and caring environment is our major theme. We would not, however, like this major thrust to obscure another shortcoming in the health care given the older person—the failure to rediagnose when a new emergency arises. It is easier to accept an established diagnosis for an elderly patient than to repeat the diagnostic effort when a new emergency occurs. It is often simpler to label a condition as terminal illness rather than to rediagnose the condition, but upon rediagnosis, a new and controllable disease may be unexpectedly found. That the extra effort can prove worthwhile is exemplified by the following case.

Over a 3-week period, headache developed in a 74-year-old retired merchant; he had difficulty in speaking and experienced weakness in the right side of the body. When he became unconscious he was admitted to the hospital with spasticity of the right arm and leg. A cerebral thrombosis had been diagnosed 2 years before, and with little effort the man's condition could have been diagnosed as the terminal stage of a second stroke. However, a more extensive diagnostic effort was considered worthwhile to insure that no error had occurred. A large clot within the skull, apparently caused by a relatively minor and unmentioned accident, was thereupon discovered and surgically removed. Antibiotics for pneumonitis, good nursing care, and restoration of the fluid and electrolyte balance greatly improved the patient's condition. After several weeks he returned to the normal activities of a man in his seventies.

### Conclusion

The major objective of health care is to improve the quality of life. We do this partly by preventing and controlling disease so that the person continues to function for as long as possible; we also alleviate the distress of disease and impairment so that life continues to be worth-

while even though accompanied by some undesirable conditions. Health providers may not always feel compelled to prolong in the aged the grave discomfort of terminal illness. Nevertheless, there is some purpose in endowing the last stages of life with those ingredients of health care that will help the dying patient feel that he is still part of a humane and caring society, which continues its concern for the individual even when health services cannot be justified by cost-benefit analyses.

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